

# Adherence to US Preventive Services Task Force recommendations for breast and cervical cancer screening for women who have a spinal cord injury

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**Context:** Women with spinal cord injury (SCI) may face barriers that result in disparities in receipt of recommended mammography and Papanicolaou testing.

**Setting:** South Carolina.

**Participants:** South Carolina women with SCI were identified using International Classification of Diseases codes in 2000–2010 Medicaid and Medicare billing data.

**Outcome measures:** Receipt of mammography and Pap testing was determined using procedure billing codes. Partial proportional odds models were estimated to examine the association between SCI and adherence with screening recommendations from the United States Preventive Services Task Force. Each individual's screening experience was classified as full adherence, partial adherence, or no screening.

**Results:** The cohort for mammography consisted of 3,173 women with SCI and 6,433 comparison women without SCI. The cohort for Pap testing consisted 5,025 women with SCI and 9,538 comparison women. Women with SCI were less likely to have full adherence with mammography recommendations (aOR = 0.69, 95% CI 0.64, 0.76) and Pap test recommendations (aOR = 0.53, 95% CI 0.49, 0.57). They were more likely to have no mammography screening (aOR = 1.44, 95% CI 1.33, 1.57) and no Pap testing (aOR = 1.89, 95% CI 1.77, 2.03) than women without SCI.

**Conclusion:** Using longitudinal data with multiple outcome levels, women with SCI were less likely to be fully adherent with receipt of recommended breast and cervical cancer screenings and more likely to have no screenings during the eligible years when compared to women without SCI.

**Keywords:** Spinal cord injuries, Mammography, Papanicolaou test, Healthcare disparities, Cancer screening

## Introduction

According to the 2010 U.S. Census, 18.3% of women in the non-institutionalized population reported disability, adjusted for age rates of disability increase with age, with disability being reported in 53.8% of women over the age of 65.<sup>1</sup> Research has shown that individuals with a disability have significantly poorer health than

those without disability.<sup>2</sup> A fragmented system of financial assistance for low-income women with disability, along with inadequate health insurance coverage, have been reported as major reasons why women with disability face barriers in accessing healthcare.<sup>3</sup> Spinal cord injury (SCI) is one underlying cause of disability. The National Spinal Cord Injury Statistical Center estimates that there are approximately 12,500 new survivors of SCI each year in the US (40 cases per million), and approximately 21% of these injuries are sustained by women.<sup>4</sup> The estimated prevalence of SCI in the United

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States is 906 per million, approximately 30% of whom are women.<sup>5</sup> Women with SCI are at risk of developing secondary conditions, including deep vein thrombosis, urinary tract infections, muscle spasms, osteoporosis, pressure ulcers, chronic pain, and respiratory complications.<sup>6</sup> An estimated 20–30% of people with SCI show significant clinical signs of depression, which negatively affects overall health and functional improvement.<sup>7</sup> Women with spinal cord injury face challenges in obtaining access to health care, including inaccessible or incompletely accessible facilities and difficulties with transportation.<sup>8,9</sup> Given the challenges to access to healthcare faced by women with SCI, receipt of clinical preventive services may also be adversely impacted.

### *Receipt of women's preventive services by women with SCI*

Two cancer screening tests for women endorsed by the US Preventive Services Task Force (USPSTF) were studied in this paper: mammography for breast cancer and cytology (Pap test) for cervical cancer. Both of these tests have been well integrated into health care for women because of their ability to detect early disease and the availability of treatment once disease is identified. Women with SCI should receive these screening tests at the same frequency as women in the general population, and receipt of such preventive services is an important marker of health equity.

Screening for breast cancer has received substantial attention since about 1 in 8 (12%) women in the United States will develop breast cancer during their lifetime. Surveillance, Epidemiology and End Results (SEER) data estimate 231,840 new cases of breast cancer in 2015, and 40,290 estimated deaths from breast cancer in 2015.<sup>10</sup> Specific recommendations regarding mammography have changed over time. In 2009, the USPSTF updated its recommendation to include biennial mammograms beginning at age 50, while the decision about screening in 40 to 49 year old women should be an individual one and take patient context into account, including the patient's values regarding specific benefits and harms.<sup>11</sup> The previous USPSTF recommendation, published in 2002, was for screening mammography every 1 to 2 years for all women older than 40 years. The USPSTF has concluded that there is insufficient evidence to recommend mammograms after age 74.<sup>12</sup> The USPSTF recommendation prior to 2002 was for mammography every 1 to 2 years for all women beginning at 50 years of age and concluding at approximately age 75 unless pathology is detected.<sup>13</sup> In 2013, 72.6% of women in the United States reported being up to date with mammography.<sup>14</sup>

US National Surveillance, Epidemiology, and End Results (SEER) data reports an estimated 12,900 new cases of cervical cancer in 2015, and 4,100 estimated deaths from cervical cancer in 2015. SEER data also reports that 0.6% of women will develop cervical cancer during their lifetime.<sup>10</sup> Guidelines released by the USPSTF in 2012 recommend Pap tests for cervical cancer screening every 3 years for women aged 21–65 years. For women aged 30–65 who wish to lengthen the screening interval, the USPSTF recommends a combination of cytology (Pap test) and HPV testing every five years. The Task Force currently recommends against screening women younger than 21 or older than 65 years (with adequate prior screening) for cervical cancer, and against screening women younger than age 30 using HPV testing.<sup>15</sup> The previous USPSTF recommendations from 2003 were to begin screening within three years of onset of sexual activity or age 21 (whichever comes first), and to screen at least every three years. The USPSTF recommended against routinely screening women older than age 65 if they had adequate recent screening with normal Pap smears and are not otherwise at high risk for cervical cancer.<sup>16</sup> Prior to 2003, USPSTF recommendations were for regular Pap tests for all women who were or had been sexually active and had a cervix. Testing was recommended beginning when the woman first engaged in sexual intercourse; adolescents whose sexual history is thought to be unreliable should be presumed to be sexually active at age 18. There was considered to be little evidence that annual screening achieves better outcomes than screening every three years.<sup>17</sup> In 2013, 80.7% of women reported being up to date with Pap testing.<sup>14</sup>

There are a number of potential barriers to breast and cervical cancer screening for women with SCI, some of which mirror general barriers to health care but others are specific to these particular screening tests. For example, in addition to encountering inaccessible entryways, hallways and bathrooms<sup>18</sup> and potentially having health care providers who are not well versed in the care of women with SCI,<sup>19,20</sup> women with SCI may have difficulty positioning themselves on exam tables for Pap testing or having a radiology technician position mammography equipment so they can remain in a wheelchair.<sup>21</sup> Previous research has found that 60% of women with SCI aged 50 or older had not had a mammogram within the past year and 39.6% of women had not received a Pap test within the previous three years.<sup>22</sup> Female veterans aged 18–65 with spinal cord injuries and disorders (SCI&D) were significantly less likely than their counterparts without SCI&D to have had a Pap test within the three years prior to the study (88%

vs. 98%, respectively); and those with SCI&D over 40 were also less likely to have had a mammogram within the past two years (84%) when compared to those without (91% screening rate).<sup>23</sup> Interestingly, a 2010 Canadian study in which all citizens had the same publicly funded insurance, showed that women with and without SCI were screened for cervical cancer at similar rates, the exception being older women (both with and without SCI) and lower income women with SCI who were less likely to be screened.<sup>24</sup>

The objective of this study was to investigate whether women with SCI receive recommended breast and cervical cancer screenings at the same rate as women without this disability.

## Methods

The data were obtained from 2000–2010 South Carolina Medicaid claim records (housed at the South Carolina Revenue and Fiscal Affairs Office), as well as South Carolina Medicare claims (from the Research Data Assistance Center\* (RESDAC)). Medicare and Medicaid are both government run programs for purchasing health care in the United States. Medicare's primary purpose is to pay for health care services for elderly individuals regardless of income,<sup>25</sup> while Medicaid primarily pays for services for low-income individuals.<sup>26</sup> In addition, many individuals with severe lifelong disability qualify for either or both programs on the basis of disability.

Using the longitudinal data from two payment sources, we categorized receipt of breast and cervical cancer screening for each woman into one of three categories: full adherence, partial adherence, and no screening.

## SCI case definition

Spinal cord injury (SCI) was identified using the following International Classification of Diseases, version 9 (ICD-9) codes:

- 343.2, 344.0x, 344.1x, 767.4x, 780.72, 806.xx, 907.2, 952.xx

We identified the women with SCI from their entire insurance file during the eleven-year study period, so we did not rely on coding at the time of the mammography or the Pap testing. Women with SCI were defined as those who had at least one of the SCI ICD-9 codes on at least one hospitalization or two outpatient encounters. The comparison group was created by matching the age of women without the SCI condition.

\*Research Data Assistance Center: This is a Center for Medicare and Medicaid (CMS) contractor that provides free assistance to academic, government and non-profit researchers interested in using Medicare and/or Medicaid data for their research.

## Inclusion and exclusion criteria

Women who were in the data set long enough (defined as a duration of at least two screening intervals: 4 years for mammography, 6 years for Pap testing) were included in the study. A total of 9,606 women (33.0% with SCI, 67.0% without SCI) were included in the model for mammography and 14,563 women (34.5% with SCI, 65.5% without SCI) were included in the model for Pap testing.

## Dependent variable—Receipt of preventive service

Receipt of mammography and Pap testing was identified using Current Procedural Terminology codes (CPT) and Healthcare Common Procedure Coding System (HCPCS) codes in the Medicaid and Medicare billing data (codes available upon request).

## Covariates

The covariates included for modeling mammography are SCI indicator (whether or not the individual had a SCI), "Age" (40–74, continuous), "Eligible Enrollment Years" (categorical variable with 4 categories for mammography: 4–6 years, 6–8 years, 8–10 years, or 10–11 years. 2 categories for Pap testing: 6–9 years, or 9–11 years), "Insurance Status" (categorical variable with 3 categories: Medicaid only, Medicare only, Medicaid and Medicare), and "Residential Area" (categorical variable with 3 categories: urban, suburban, or rural). The modeling for Pap testing included one additional confounder, "Hysterectomy," which was a dichotomous variable indicating whether a woman had a hysterectomy during the study period. We did a sensitivity analysis for which data associated with women who had hysterectomy were removed from the analysis, and we found only negligible changes in the coefficients and no changes in the significance levels for the models. Thus, we included the hysterectomy variable in the final reported models.

Based on the USPSTF recommendations in place during the study period, we used following criteria for adherence with mammography:

- 2000–2001: Mammography at least every 2 years for women 50–69 years of age
- 2002–2007: Mammography at least every 2 years for women 40–74 years of age
- 2008–2010: Mammography at least every 2 years for women 50–74 years of age.

The criteria for Pap testing were:

- 2000–2002: Pap testing at least every 3 years for women 18–65 years of age
- 2003–2010: Pap testing at least every 3 years for women 21–65 years of age

We assigned each response variable to one of three levels: “Full adherence” for women who followed the recommendations approximately on time for all screening intervals, “Partial adherence” for women who had preventive screenings but did not receive a screening during a particular time interval, and “No screening” for women who were not screened at all during their eligible years of enrollment.

Women were categorized based on the amount of time they were eligible in the data set during the study period. These categories were based on the number of screening intervals of follow-up available, during which a woman was within the recommended age for the service being examined. There were 4 categories for mammography (4–6, 6–8, 8–10,  $\geq 10$  years of eligible enrollment) and 2 categories for Pap testing (6–9,  $\geq 9$  years of eligible enrollment). The outcome variable for each woman in our study was determined based on the number of screening services she had during her years of eligible enrollment. A woman was considered to be adherent with screening during a given interval when the screening was performed during the eligible years; the time interval between each screening and the previous one had to be greater than 1 year for both mammography and Pap testing and less than 2.5 or 3.5 years for mammography or Pap testing respectively. This provides 6 months of leeway for women who were off schedule for any reason.

### Statistical approach

Cumulative logit models with proportional-odds assumption were used. We chose “Full adherence” to be the baseline group first. The two sets of estimated parameters are the effects of covariates on the log odds of being fully adherent and the log of odds of being fully/partially adherent. We then changed the baseline group to be the “No screening,” so that we could obtain the log odds of having no screening and the log odds of being in “No screening/Partial adherence” groups.

The score test was used to check the proportional odds assumption. The test result indicated that the effects of age, eligible enrollment years, insurance status and hysterectomy (Pap testing only) did not satisfy the assumption, which means their effects on the odds of being fully adherent and the odds of being fully/partially adherent were different.

## Results

### Mammography

One-fifth of the women with SCI were fully adherent to USPSTF mammography recommendations during the study period, compared to one-fourth of the women in

the reference group. About one-third of the women with SCI had no screening during the study period, while one-fourth of the women without SCI had no screening (Table 1).

The adjusted odds ratio of full adherence with mammography recommendations for women with SCI compared with women without SCI was 0.69 (95% CI = 0.64, 0.76), after adjusting for other covariates (Table 2). Increasing age was associated with greater odds of full adherence. Odds of full adherence were also greater among women enrolled in both Medicare and Medicaid and in those enrolled in Medicare only, compared to women enrolled in Medicaid only. Women living in suburban or rural areas had lower odds of full adherence. Odds of full adherence varied with duration of Medicaid/Medicare enrollment, but not in a consistent pattern.

Women with SCI had greater odds of not having a mammogram during the study period (aOR = 1.44, 95% CI 1.33, 1.57). Increasing age, and living in a rural or urban residence was associated with greater odds of no screening. There was variation by duration of Medicaid/Medicare enrollment, but not in a consistent pattern.

### Pap testing

Full adherence was more common for Pap testing than for mammography (43.9% of women with SCI versus 58.4% of women without SCI). About one-fourth of the women with SCI and one-seventh of the women without SCI did not have a Pap test during their years of eligible enrollment.

The adjusted odds ratio for full adherence with Pap testing in women with SCI versus women without was 0.53 (95% CI = 0.49, 0.57). Odds of being fully adherent to Pap testing were higher in women with more than 9 years of eligible enrollment than the 6–9 years of eligible enrollment group. Having a hysterectomy during the study period was also positively associated with full adherence. Increasing age and living in a suburban or rural area were both associated with lower odds of full adherence (Table 3).

Women with SCI had significantly greater odds of having no screening (aOR = 1.89, 95% CI 1.77, 2.03) than women without SCI. Odds of not having a Pap test were also higher in women who were older, those with Medicare insurance only, and those living in a suburban or rural area. Women with more years of enrollment were less likely to have no screening.

There were no substantive changes in any of the above results when we repeated the analyses, limiting the models to women who did not experience a hysterectomy during the study period.

**Table 1** Percentage of demographic characteristics of women with and without SCI stratified by mammogram and Pap testing, from South Carolina medical claim records and other sources<sup>†</sup>, n(%)

	Mammogram		Pap Testing	
	Women with SCI <sup>†</sup> (n = 3173)	Women without SCI <sup>†</sup> (n = 6433)	Women with SCI <sup>†</sup> (n = 5025)	Women without SCI <sup>†</sup> (n = 9538)
Response				
Full adherence	19.57%	24.72%	43.88%	58.37%
Partial adherence	48.00%	50.13%	32.40%	27.34%
No screening	32.43%	25.15%	23.72%	14.29%
Hysterectomy				
Yes	-	-	30.93%	22.12%
No	-	-	69.07%	77.88%
Age				
20–30 years	-	-	22.65%	23.42%
30–40 years	-	-	22.17%	21.79%
40–50 years	27.48%	26.12%	23.54%	22.81%
50–60 years	39.14%	38.74%	23.66%	23.77%
60–74 years	33.38%	35.15%	7.98%	8.21%
Eligible enrollment years				
Mammography 4–6 years	18.09%	18.39%	-	-
6–8 years	22.94%	21.92%	-	-
8–10 years	32.43%	33.23%	-	-
10–11 years	26.54%	26.46%	-	-
Pap Test 6–9 years	-	-	28.06%	28.84%
9–11 years	-	-	71.94%	71.16%
Insurance status				
Medicaid only	85.00%	86.04%	89.33%	93.62%
Medicare only	9.86%	13.32%	7.04%	5.85%
Medicare and Medicaid	5.14%	0.64%	3.62%	0.53%
Residential location				
Urban	75.89%	76.56%	74.71%	75.68%
Suburban	18.00%	16.90%	19.58%	17.58%
Rural	6.11%	6.54%	5.71%	6.74%

<sup>†</sup> Other sources: South Carolina Revenue and Fiscal Affairs Office and Health and Demographics, and South Carolina Medicare claims from ResDAC. <sup>‡</sup> SCI: Spinal cord injury.

## Discussion

In this study, we analyzed eleven years of South Carolina Medicare and Medicaid data to investigate the differences in receipt of mammography and Pap testing for women with SCI compared to those

without SCI. Our results showed that women with SCI are statistically significantly less likely to fully adhere with USPSTF recommendations for breast and cervical cancer screening, compared to women without SCI. Similarly, women with SCI were also more likely to

**Table 2** Adjusted odds ratios for women being fully adherent or not being screened with USPSTF<sup>a</sup> breast cancer screening recommendations for mammography

Covariates	Full Adherence		No Screening	
	OR <sup>b</sup>	95% CI <sup>c</sup>	OR <sup>b</sup>	95% CI <sup>c</sup>
SCI <sup>d</sup> vs. comparison group	0.694	(0.639, 0.755)	1.440	(1.325, 1.565)
1 yr. increase in age	1.008	(1.002, 1.014)	1.014	(1.009, 1.019)
Medicare and Medicaid vs. Medicaid only	1.791	(1.318, 2.435)	1.037	(0.758, 1.420)
Medicare only vs. Medicaid only	1.272	(1.102, 1.467)	0.920	(0.792, 1.070)
6–8 yrs. of enrollment vs. 4–6 yrs. of enrollment	0.703	(0.600, 0.824)	0.671	(0.590, 0.765)
8–10 yrs. of enrollment vs. 4–6 yrs. of enrollment	0.950	(0.826, 1.094)	0.320	(0.281, 0.363)
≥ 10 yrs. of enrollment vs. 4–6 yrs. of enrollment	1.234	(1.064, 1.431)	0.171	(0.146, 0.199)
Suburban residence vs. urban residence	0.899	(0.811, 0.996)	1.113	(1.004, 1.233)
Rural residence vs. urban residence	0.673	(0.574, 0.789)	1.486	(1.267, 1.742)

Mammography procedures were identified using ICD-9 codes (V76.10, V76.11, V76.12, V76.19), CPT codes (77051, 77052, 77055–77059) and HCPCS codes (G8111, G0202, G0206).<sup>a</sup> USPSTF: U.S. Preventive Services Task Force. <sup>b</sup> OR: Odds Ratio. <sup>c</sup> CI: Confidence Interval. <sup>d</sup> SCI: Spinal Cord Injury.

**Table 3** Adjusted odds ratios for women being fully adherent or not being screened with USPSTF<sup>a</sup> cervical cancer screening recommendations for Pap testing

Covariates	Full Adherence		No Screening	
	OR <sup>b</sup>	95% CI <sup>c</sup>	OR <sup>b</sup>	95% CI <sup>c</sup>
SCI <sup>d</sup> vs. comparison group	0.528	(0.494, 0.565)	1.893	(1.769, 2.025)
1 yr. increase in age	0.962	(0.959, 0.965)	1.057	(1.052, 1.061)
Medicare and Medicaid vs. Medicaid only	0.795	(0.603, 1.047)	0.934	(0.677, 1.288)
Medicare only vs. Medicaid only	0.545	(0.470, 0.632)	1.224	(1.038, 1.442)
≥ 9 yrs. of enrollment vs. 6–9 yrs. of enrollment	1.339	(1.242, 1.445)	0.479	(0.437, 0.525)
Suburban residence vs. urban residence	0.866	(0.796, 0.941)	1.155	(1.063, 1.256)
Rural residence vs. urban residence	0.774	(0.679, 0.882)	1.292	(1.133, 1.472)
Hysterectomy vs. no hysterectomy	1.315	(1.215, 1.424)	1.025	(0.928, 1.134)

Pap test procedures were identified using ICD-9 codes (V67.01, V72.31, V76.2, V76.47), CPT codes (88141–88143, 88147, 88148, 88150, 88152–88154, 88164–88167, 88174, 88175), and HCPCS codes (P3000, P3001, Q0091, G0123, G0124, G0143–G0145, G0147, G0148).<sup>a</sup> USPSTF: U.S. Preventive Services Task Force. <sup>b</sup> OR: Odds Ratio. <sup>c</sup> CI: Confidence Interval. <sup>d</sup> SCI: Spinal Cord Injury.

receive no screening during the study period. These findings are generally consistent with previous reports about preventive service disparities for people with SCI.

However, this study provides a unique contribution to the literature by using a more sensitive method of calculating adherence by using eleven years of longitudinal data from two insurance sources that provide coverage for health services for people with disability. This allowed us to not only observe one episode of adherence but to determine if women follow the changing recommended screenings for their age group, over time. Moreover, we categorized adherence as “Full adherence,” “Partial adherence,” and “No screening,” based on the frequency of screening during the study period, as opposed to most studies that examine only a single screening interval and categorize individuals as “screened” or “not screened.” By adding a partially screened group, it gives researchers more flexibility on interpreting the other two odds, as well as information on women with SCI who may have some, but insufficient screening. Additionally, our use of insurance billing data to document receipt of screening services is a strength, as it eliminates the need to rely upon accurate patient recall of services received.

The use of merged Medicaid and Medicare data allowed us to identify screening tests through multiple reimbursement methods. Women who were insured by both Medicaid and Medicare were more likely to have a mammogram than women who had only one of the insurance sources. We observed 91.6% of Pap tests were detected in Medicaid, while only 83.9% of mammography screening episodes were detected in Medicaid only. Thus, if only Medicaid was used as a data source for our analysis of preventive services use for women with SCI, we could underreport adherence as we would miss 6.3% of the women who had a Pap test covered by Medicare and 12.7% of the women who had a mammogram.

In order to improve breast and cervical cancer adherence rates for women with SCI we need to understand the possible explanations for the lower rates of screening in women with SCI, including barriers and challenges. A recent review of 25 papers identified three primary barriers to receipt of screening for breast and cervical cancer in women with a disability: lack of health insurance, factors related to the actions and skills of health-care workers, and physical barriers to access.<sup>27</sup> With regard to lack of health insurance, a 2005 study using data from the 2000 and 2005 National Health Interview Survey, demonstrated that 31% of women with disability, compared to 13% of women without disability, reported financial burden or being uninsured as the main reason for not having had a Pap test.<sup>28</sup> Research findings have also shown that women with private health insurance had increased rates of mammography screening, compared to those without private insurance; this is of relevance to our study given our population of Medicaid and Medicare beneficiaries.<sup>29</sup>

With regard to barriers related to healthcare workers, one study revealed that 20% of women with disability were unable to find a doctor who understood their disability.<sup>30</sup> In addition, many women with disability report not having a primary care provider;<sup>31</sup> women who have a primary care provider and a usual site of care are more likely to have higher rates of preventive screening.<sup>32</sup> Physicians’ attitudes, level of knowledge, and their understanding of the disability pose barriers to women with disability receiving preventive care.<sup>30</sup> More women with disability reported that doctors did not inform them of the importance of Pap tests,<sup>33</sup> or the importance of mammography.<sup>34</sup> In addition, older women (aged >65 years) with a disability were less likely to be advised to have screening,<sup>34,35</sup> an unfortunate finding given the increased risk of cancer with increasing age.<sup>36</sup> Stereotypes and misconceptions

about women with disability also play a role; providers may believe that women with disability do not need mammograms or Pap smears as they are less likely to develop cancer, are not sexually active, or are unable to have screening equipment used properly on them due to their disability.<sup>37</sup>

On the other hand, there is evidence that creating positive experiences for women with disability may encourage them to participate in regular and timely cancer screening;<sup>38</sup> a 2008 study found that women who had better quality screening experiences were more likely to receive timely, regular mammograms and Pap tests.<sup>39</sup> It is of note that the adherence rates for mammography was lower than for mammography. This could be attributable to the fact that Pap tests can be provided in the physician's office at the time the screening recommendation is made, whereas mammography typically requires a separate visit to a radiographic imaging center, thus exacerbating barriers related to transportation. With regard to physical barriers, 22% of women with disability reported having difficulty accessing health facilities, offices of health providers, and to medical equipment used for screening, such as mammography machines and examination tables used for Pap tests.<sup>35</sup> Fourteen percent of women with a disability reported transportation issues as the key deterrent for cancer screening, compared to 5% among women without functional limitations.<sup>39</sup> In addition, women with multiple disabilities reported even greater barriers with access, parking, and transportation.<sup>34</sup>

Another barrier may be mental health issues such as depression; as 20–30% of women with spinal cord injury have shown clinically significant signs of depression.<sup>7</sup> Women who are clinically depressed are less likely to receive screening mammograms, therefore, women with disability who are also depressed may be even less likely to receive recommended screenings.<sup>40,41</sup> Additional research is needed to examine the extent to which depression or other mental health concerns may specifically affect screening rates in women with SCI. Lack of information regarding the importance of screening and the ways women can be accommodated may also decrease the likelihood of women with SCI receiving screening mammograms.<sup>38</sup>

Furthermore, a specific barrier to Pap testing faced by women with SCI is the possibility of the screening test itself triggering autonomic dysreflexia, which is characterized by hypertension, and its sequelae of pilo-erection, flushing, pounding headache, sweating, and blurred vision. Autonomic dysreflexia can be triggered by speculum use or perineal manipulation during Pap tests in some women with SCI. Preventive strategies that can be undertaken prior to the pelvic examination

to decrease the risk of autonomic dysreflexia include emptying of the bowel and bladder, coating the speculum with anesthetic jelly, or administering prophylactic nifedipine thirty minutes prior to the procedure.<sup>42–44</sup> Women and/or health care providers may be concerned about triggering autonomic dysreflexia during a Pap test, and, thus, may defer getting screened.

There were a number of limitations of our study because the analysis was done using Medicare and Medicaid billing claims data. For patients who were reimbursed by other payers, we could not capture these claims. Since we used only administrative data, we do not have information about why some women did not undergo screening. And race/ethnicity information was not available for our study sample. Because we relied on the coding by health care providers and coders to identify cases of SCI it is likely that there were some errors in case classification, and these errors could affect the estimated probability of being adherent to the screening recommendations. We did not obtain information on the specialty of the health care provider who made the referral for mammography, nor did we specify the specialty of the provider who performed Pap testing. Moreover, our study population was limited to women in SC, a state in the southern United States. The findings may or may not be generalizable to women in other states or other countries. For example, an analysis of billing data in Canada did not find significant disparities in cervical cancer screening for women with SCI.<sup>24</sup> Additional research is needed to identify the reasons for disparities in SC but not Canada, and to examine potential disparities in other countries.

Information collected directly from both patients and health care providers would be helpful in identifying specific barriers that need to be addressed to improve screening rates for women with SCI, but this could not be done with administrative data. Finally, we did not link our data to cancer registry or mortality data, so we cannot necessarily conclude that the reduced rates of screening observed in this study translate to greater mortality from breast and cervical cancer in women with SCI, though there is at least one other study that did note reduced survival in the context of breast cancer, for women with a disability.<sup>45</sup>

## Conclusions

When using 11 years of longitudinal data and examining different levels of screening adherence, women with SCI living in South Carolina were found to be less likely than their counterparts without SCI to receive recommended screening for breast and cervical cancer via mammography and Pap testing. Further research should focus on

evaluating the efficacy of actions that remove barriers faced by women with SCI in receiving these screening services.

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## ORCID

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## References

- Brault MW. Americans with disabilities: 2010. Washington (DC): U.S. Census Bureau; 2012; Current Population Reports; 70–131.
- Rimmer JH, Rowland JL. Health promotion for people with disabilities: implications for empowering the person and promoting disability-friendly environments. *J Lifestyle Med* 2008;2:409–20.
- National Council on Disability. The current state of health care for people with disabilities. Available from: <http://www.ned.gov/publications/2009/Sept302009#Overview>
- National Spinal Cord Injury Association. Women's issues [cited 2016 Feb 6]. Available from: <http://www.spinalcord.org/resource-center/askus/index.php?pg=kb.printer.friendly&id=38#p1571>
- Singh A, Tetreault L, Kalsi-Ryan S, Nouri A, Fehlings MG. Global Incidence and prevalence of traumatic spinal cord injury. *Clin Epidemiol* 2014;6:309–31.
- National Spinal Cord Injury Center. 2014 Facts and figures at-a-glance [cited 2016 Feb 6]. Available from: <https://www.nscisc.uab.edu/>
- World Health Organization. Spinal Cord Injury Factsheet. November 2013 [cited 2016 Feb 6]. Available from: <http://www.who.int/mediacentre/factsheets/fs384/en/>
- Stillman MD, Frost KL, Smalley C, Bertocci G, Williams S. Health care utilization and barriers experienced by individuals with spinal cord injury. *Arch Phys Med Rehabil* 2014;95(6):1114–26.
- Barclay L, McDonald R, Lentin P. Social and community participation following spinal cord injury: a critical review. *Int J Rehabil Res* 2015;38(1):1–19.
- Surveillance, Epidemiology and End Results Program. SEER stat fact sheets: breast cancer [cited 2016 Feb 6]. Available from: <http://seer.cancer.gov/statfacts/html/cervix.html>
- United States Preventive Services Task Force. Screening for breast cancer: U.S. Preventive Services Task Force recommendation statement. *Ann Intern Med* 2009;151(10):716–26.
- United States Preventive Services Task Force. Screening for breast cancer: U.S. Preventive Services Task Force Recommendation Statement. *Ann Intern Med* 2002;137(5\_Part\_1):344–46.
- US Preventive Services Task Force. Guide to clinical preventive services: report of the U.S. Preventive Services Task Force. 2nd edition. Baltimore (MD): Williams & Wilkins; 1996. 7, Screening for breast cancer [cited 2016 Feb 6]. Available from: <http://www.ncbi.nlm.nih.gov/books/NBK15484/>
- Sabatino SA, White MC, Thompson TD, Klabunde CN; Centers for Disease Control and Prevention (CDC). Cancer screening test use—United States, 2013. *MMWR Morb Mortal Wkly Rep* 2015;64(17):464–8.
- United States Preventive Services Task Force. Screening for cervical cancer: U.S. Preventive Services Task Force recommendation statement. *Ann Intern Med* 2012;156:880–91, W312.
- No author listed. Screening for cervical cancer: recommendations and rationale. *Am Fam Physician* 2003;67(8):1759–66.
- US Preventive Services Task Force. Guide to clinical preventive services: report of the U.S. Preventive Services Task Force. 2nd edition. Baltimore (MD): Williams & Wilkins; 1996. 9, Screening for cervical cancer [cited 2016 Feb 6]. Available from: <http://www.ncbi.nlm.nih.gov/books/NBK15479/>
- Iezzoni LI, McCarthy EP, Davis RB, Siebens H. Mobility impairments and use of screening and preventive services. *Am J Public Health* 2000;90(6):955–61.
- Smeltzer S. Preventive health screening for breast and cervical cancer and osteoporosis in women with physical disabilities. *Fam Community Health* 2006;29:355–43S.
- Kroll T, Jones GC, Kehn M, Neri MT. Barriers and strategies affecting the utilization of primary preventive services for people with physical disabilities: a qualitative inquiry. *Health Soc Care Community* 2006;14(4):284–93.
- Schopp LH, Sanford TC, Hagglund KJ, Gay JW, Coatney MA. Removing service barriers for women with physical disabilities: Promoting accessibility in the gynecologic care setting. *J Midwifery Womens Health* 2002;47(2):74–9.
- Stillman MD, Frost KL, Smalley C, Bertocci G, Williams S. Health care utilization and barriers experienced by individuals with spinal cord injury. *Arch Phys Med Rehabil* 2014;95:1114–26.
- Lavelle SL, Weaver FM, Smith B, Chen K. Disease prevalence and use of preventive services: comparison of female veterans in general and those with spinal cord injuries and disorders. *J Womens Health (Larchmt)* 2006;15(3):301–11.
- Guilcher SJ, Newman A, Jaglal SB. A comparison of cervical cancer screening rates among women with traumatic spinal cord injury and the general population. *J Womens Health (Larchmt)* 2010;19(1):57–63.
- Centers for Medicare and Medicaid Services. Medicare program general information [cited 2016 Feb 6]. Available from: <https://www.cms.gov/Medicare/Medicare-General-Information/MedicareGenInfo/index.html>
- Medicaid Official Website. Program history [cited 2016 Feb 6]. Available from: <https://www.medicaid.gov/about-us/program-history/program-history.html>
- Ramjan L, Cotton A, Algosio M, Peters K. Barriers to breast and cervical cancer screening for women with physical disability: a review. *Women Health*. 2015 Sep 1:1–16. Epub ahead of print.
- Drew JA, Short SE. Disability and pap smear receipt among U.S. women, 2000 and 2005. *Perspect Sex Reprod Health*. 2010;42(4):258–66.
- Ahmed NU, Smith GL, Haber G, Belcon MC. Are women with functional limitations at high risk of underutilization of mammography screening? *Women Health Issues* 2009;19(1):79–87.
- Harrington AL, Hirsch MA, Hammond FM, Norton HJ, Bockenek WL. Assessment of primary care services and perceived barriers to care in persons with disabilities. *Am J Phys Med Rehabil* 2009;88(10):852–63.
- Morrison EH, George V, Mosqueda L. Primary care for adults with physical disabilities: Perceptions from consumer and provider focus groups. *Fam Med* 2008;40(9):645–51.
- Allen SM, Wieland S, Griffin J, Gozalo P. Continuity in provider and site of care and preventive services receipt in an adult Medicaid population with physical disabilities. *Disabil Health J* 2009;2(4):180–7.
- Ramirez A, Farmer GC, Grant D, Papachristou T. Disability and preventative screening: results from the 2001 California Health Interview Survey. *Am J Public Health* 2005;95(11):2057–64.
- Yankaskas BC, Dickens P, Bowlin M, Jarman MP, Luken K, Salisbury K, et al. Barriers to adherence to screening mammography among women with disabilities. *Am J Public Health* 2010;100(5):947–53.

- 35 Chevarley FM, Thierry JM, Gill CJ, Ryerson AB, Nosek MA. Health, preventative health care, and health care access among women with disabilities in the 1994–1995 national health interview survey, supplement on disability. *Women Health Issues* 2006;16(6):297–312.
- 36 Iezzoni LI, Frakt AB, Pizer SD. Uninsured persons with disability confront substantial barriers to health care services. *Disabil Health J* 2011;4(4):238–44.
- 37 Lin JD, Chen SF, Lin LP, Sung CL. Self-reports of Pap smear screening in women with physical disabilities. *Res Dev Disabil* 2011;32(2):456–61.
- 38 Llewellyn G, Balandin S, Poulos A, McCarthy L. Disability and mammography screening: intangible barriers to participation. *Disabil Rehabil* 2011;33(19–20):1755–67.
- 39 Liu SY, Clark MA. Breast and cervical cancer screening practices among disabled women aged 40–75: does quality of the experience matter? *J Womens Health (Larchmt)* 2008;17(8):1321–9.
- 40 Aggarwal A, Freund K, Sato A, Adams-Campbell LL, Lopez AM, Lesin LS, *et al.* Are depressive symptoms associated with cancer screening and cancer stage at diagnosis among postmenopausal women? The Women's Health Initiative observational cohort. *J Womens Health (Larchmt)* 2008;17(8):1353–61.
- 41 Todd A, Stuijbergen A. Breast cancer screening barriers and disability. *Rehabil Nurs* 2012;37(2):74–9.
- 42 Bates CK, Carroll N, Potter J. The challenging pelvic examination. *J Gen Intern Med* 2011;26(6):651–7.
- 43 Krassioukov A, Blackmer J, Teasell RW, Eng JJ. Autonomic dysreflexia following spinal cord injury. spinal cord injury rehabilitation evidence (2012). Available from: <http://www.scireproject.com/sites/default/files/>
- 44 Eng JJ, Teasell RW, Miller WC, Wolfe DL, Townson AF, Hsieh JTC, *et al.* Spinal cord injury rehabilitation evidence: methods of the SCIRE systematic review. *Top Spinal Cord Inj Rehabil* 2007;13(1):1–10.
- 45 McCarthy EP, Ngo LH, Roetzheim RG, Chirikos TN, Li D, Drews RE, *et al.* Disparities in breast cancer treatment and survival for women with disabilities. *Ann Intern Med* 2006;145:637–45.